

## Joint Statement for International Thalassaemia Day 2025

*TIF - Thalassaemia International Federation & EBCOG - European Board & College of Obstetrics and Gynaecology*

### **Thalassaemia: A Call for Unity, Advocacy, and Patient-Centric Care**

Thalassaemia is a genetic blood disorder that affects the body's ability to produce haemoglobin, leading to varying degrees of anaemia, fatigue, and other serious complications. The severity of the condition depends on the type of thalassaemia, making expert care essential for effective treatment and management. It is estimated that approximately 100 million people worldwide carry genes responsible for thalassaemia, with more than 300,000 babies born annually with severe forms of the disease. However, these figures are grossly underestimated due to the lack of national patient registries and the absence of well-implemented prevention programmes in many highly affected countries.

International Thalassaemia Day, observed annually on May 8, serves as a global platform to raise awareness about thalassaemia among the public, while urging researchers, policymakers, and healthcare professionals to address the needs of those living with this chronic and often debilitating blood disorder. **This day is a timely reminder that no one should face challenges alone, and that progress relies on collective action.** Collaboration across medical disciplines, as well as engagement among key stakeholders—including patients, families, academia, the research community, and regulatory bodies—is essential for advancing care, research, and policy development.

The Thalassaemia International Federation (TIF), the leading global advocate for individuals with thalassaemia, and the European Board & College of Obstetrics and Gynaecology (EBCOG), committed to improving the health of women and newborns, stand together in solidarity under this year's theme: **"Together for Thalassaemia: Uniting Communities, Prioritizing Patients."** This theme underscores the importance of fostering a patient-centered approach to thalassaemia care, ensuring that individuals are treated with dignity and that their holistic well-being is prioritized.

In Europe, thalassaemia is classified as a rare disease, except in Mediterranean countries where it is endemic. However, due to increasing migration and

mobility trends, its prevalence is rising in several other European nations. Unfortunately, misdiagnosis and underdiagnosis remain significant challenges, particularly in underserved and migrant communities. Furthermore, many EU countries struggle to provide optimal care due to the rarity of the condition and the lack of preparedness within national healthcare systems. Women with thalassaemia, especially those of migratory background, face additional challenges during pregnancy and childbirth, requiring tailored and specialized care to safeguard both maternal and neonatal health.

As TIF and EBCOG, we call upon healthcare authorities, policymakers, and the global medical community to:

- **Promote education, knowledge dissemination, and best practices** in the diagnosis, management, and prevention of thalassaemia.
- **Ensure timely access to comprehensive, multidisciplinary care** for all individuals living with thalassaemia, including **specialised maternal and reproductive healthcare** for women with the condition.
- **Promote national and international policies** that prioritise **carrier screening, genetic counselling, and prenatal diagnosis**, particularly in high-prevalence and at-risk populations.
- **Encourage investment in research** to advance **innovative therapies and curative approaches** that can improve survival and quality of life.
- **Amplify the patient voice** in shaping healthcare policies, ensuring that those directly affected are active partners in the design and evaluation of services.

TIF and EBCOG reaffirm their commitment to ensuring that individuals with thalassaemia—particularly women and children—receive equitable, high-quality, and compassionate care. By working together, we can drive meaningful change, reduce health disparities, and ultimately create a future where thalassaemia is no longer a barrier to a fulfilling and healthy life.

***Together, we can make a lasting impact. Together, we stand for thalassaemia.***

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